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‘Nudging’ deceased donation through an opt-out system: a libertarian approach or manipulation?

Nudges involve designing social ‘choice contexts’ to promote what ‘experts’ regard as beneficial for individuals and the society, by making the ‘right’ choices easier. The most common form of nudge for organ donation in Europe is presumed consent, commonly referred to as an ‘opt-out’ model. Opt-out is a type of nudge because it induces people to become organ donors by establishing organ donation as the default option and taking advantage of individuals’ tendency to prefer the status quo (Mackay and Robinson 2016). In 2008, at least 20 European countries had implemented such a system (Rithalia et al. 2009a). Since then, new countries have considered changing their model from an opt-in system –where individuals are able to make the choice to register as potential donors- to opt-out, including Romania (Grigoras 2010) and the UK (Department of Health 2008), with Wales moving to presumed consent in Dec 2015 (National Assambley for Wales).

Opt-out advocates claim that this is an acceptable way of increasing the number of available organs and promoting society’s general interests. They also believe that presumed consent laws do not violate the principle of autonomy (Gill 2004) insofar as, according to nudge theory (Thaler and Sunstein 2008), freedom of choice is preserved

with the option to register an unwillingness to donate and the default choice is easy to avoid.

MacKay and Robinson acknowledge that nudges for organ donation registration can play a positive role through increasing donation and transplantation rates, which might ultimately make these policies politically appropriate. However, they also underline that their use comes with a moral cost; by bypassing people's deliberative capacities, nudges corrupt their decision-making and hurt their capacity for self determination (Mackay and Robinson 2016). Whether or not opt-out is an effective way for achieving the availability of organs for transplantation and whether or not it is compatible with the respect of people's autonomy remains controversial.

SOCIETAL GOAL

Although countries with a presumed consent model typically have higher organ donation rates, opt-out legislation has not been demonstrated to act, by its own merits, as a sufficient factor explaining a significant increase of national organ donation rates (Abadie and Gay 2006; Rithalia et al. 2009). Belgium, which is often cited as a country which doubled its OD rates only three years after implementing opt-out, simultaneously implemented other measures to reorganize the donation system to which its good results could also be attributable, and formed a key influence on the relatively high donation rates in Spain (Organ Donation Taskforce 2008; Matesanz et al. 2011). It is also notable that OD rates in Sweden did not increase after the opt-out legislation was passed (Backman et al 2002). Rithalia and colleagues thus concluded that “the available evidence suggests that presumed consent is associated with increased organ donation rates, even when other factors are accounted for. However, it cannot be inferred from

this that the introduction of presumed consent legislation per se will lead to an increase in organ donation rates” (Rithalia et al. 2009b, 7).

RESPECT FOR AUTONOMY

It is sometimes argued, in favor of opt-out, that individuals have lost all interest once they are dead (Isdale and Savulescu 2015), and that their organs will not be procured without family authorization anyway –most opt-out countries allow families to override potential donors’ wish to donate and their authorization is eventually considered necessary (Wilkinson 2005). However, opt-out is not only about having one’s organs procured after death. In countries like Spain or France, where uncontrolled donation after circulatory death is performed from patients who suffer an out-of-hospital circulatory arrest, potential *donors*’ presumed consent is also invoked to justify a number of pre-mortem interventions (e.g. chest compression, mechanical ventilation, heparin administration) that are not intended to be therapeutic, but strictly to preserve their organs and benefit their potential recipients (De Lora 2014). These interventions are done with no proof whatsoever of patient’s willingness to donate *or* family authorization (Rodríguez-Arias et al. 2013). Some authors have claimed that a generic explicit consent (i.e. “I agree with being registered as an organ donor”) would not suffice for making these non-therapeutic interventions compatible with patients’ respect and non-instrumentalization (Verheijde et al. 2009). If their concerns with a generic form of explicit consent are reasonable, the more so with presumed consent.

Another common belief is that the implementation of presumed consent policies provides every individual with the option to opt out of this status (MacKay and Robinson 2016). However, in some European opt-out countries, such as Spain, Norway

and Croatia, refusal registries or a standard card enabling people to refuse to donate are non-existent (Rithalia et al. 2009), which goes against the key requirement of ‘nudge’ theory that individuals must remain at liberty to behave differently and to easily choose against the default status quo.

The degree of wrongness created by opt-out not only depends on the proportion of people for which the default would make it harder for them to choose their preferred option not to donate (Makay and Robinson 2016) but also depends on the proportion of citizens who would even reject the use of this form of influence if they were aware of it. A qualitative study conducted by Lauri (2009) showed that presumed consent can be perceived by lay people as an intrusive policy that violates the rights of individuals to refuse to donate their organs. In Spain, 75% of the respondents to a public survey rejected presumed consent as a form of abuse of authority (Conesa 2008). There is also evidence suggesting that important proportions of the population in countries with opt-out laws are not aware of this policy. For example, a recent study in Poland reported that 62% of medical students and only 23% of non-medical academic students were aware of that policy (Nowak et al. 2014), and a similar situation was identified by a survey of health sciences students in Greece (Symvoulakis et al, 2014), and France (Mekahli et al. 2009), where only 51% of the student respondents were aware of the law. On average, less than three in ten Europeans report that they know the regulations in their country for organ donation and transplantation (European Commission 2010). The fact that some citizens perceive organ donation as having limited topical relevance as they do not consider death and organ donation as a matter of personal concern, -might partially account for lack of knowledge, clarity and precision about legislation (Morgan et al. 2016, 16). Ultimately, lack of knowledge about the model of donation is a

constraint on autonomy and choice regarding a morally relevant decision. Even in countries where refusal registries exist (e.g. France, Portugal, Belgium and Sweden) that lack of knowledge precludes the assumption that an individual not registered on such a registry accepts posthumous organ procurement (Guibet-Lafaye and Kreis 2013).

RESPECT FOR DIVERSITY

Whereas nudges assume both common values among the population and the importance of the immediate choice context, dispositions are known to vary between social groups reflecting differences in history, geography and personal experience. Individuals' choices are thus socially bounded and occur within the constraints of dispositions that are acquired and internalized through past experience, rather than being purely influenced by the immediate choice context (Morgan et al. 2015). For example, both faith beliefs and feelings of marginalization in the society have been consistently identified as key influences on the greater prevalence of negative responses to deceased donation among minority ethnic groups (Morgan et al. 2013; Siminoff 2000). A presumed consent system may also unduly impact on socially disadvantaged groups because of their relatively low knowledge of the organ donation system and requirements for opt-out (Morgan et al., 2013). Every strategy likely to raise OD needs to be carefully considered in virtue of both its conflicts with core ethical values and its capacity to reinforce or undermine public trust including its particular impact on disadvantaged sub-groups in the population.

CONCLUSIONS

Mackay and Robinson have pointed out that presumed consent for organ donor registration is a form of nudge that involves reason-bypassing nonargumentative influence –one of the forms of ‘manipulation’ identified by Blumenthal-Barby (2012). We have also presented evidence suggesting that, by withholding options and information from citizens, presumed consent is commonly implemented in a way that involves a more elemental form of manipulation through omission, with many people in opt-out countries becoming organ donors although not aware they would be treated as such.

We have suggested that respect for autonomy and respect for diversity are important moral reasons for public authorities in opt-out countries to be more transparent about the conditions under which people become organ donors. This does not necessarily imply a rejection of opt-out policies –which might after all be instrumental for increasing organ procurement rates- but an invitation to invest more efforts to inform individuals of the choices they are being induced to make.

We believe that there are also strategic reasons for increased transparency given that the long-term success of organ donation policies relies not only on respect for commonly shared ethical values but also on the capacity to preserve public trust in the system (Rodríguez-Arias 2013). In Europe, one in five citizens unwilling to donate cited distrust in the system as the reason not to donate one’s own organs or those of deceased close relative (European Commission 2010). Transparency can therefore play a crucial role in assuring the long-term success of organ transplantation policies. People need good organ donation systems no less than good organ donation systems need people.

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